

INTRODUCTION

Cancer is a generic term for a group of over a hundred chronic diseases. Cancer can involve any tissue have many different forms in each body area. Most cancers are named for the type of cell or organ in which they start. If a cancer spreads (metastasizes) the new tumor bears the same name as the original (primary) tumor. Untreated cancers can cause serious illness and end death *American Cancer Society [ACS] (2013)*.

Cancer account for approximately 580,350 of all deaths worldwide, estimated 1, 660, 290 million new cancer cases in 2013 worldwide. It is the leading cause of death in the developed countries and the second leading cause of death in the developing countries. As the world's population continues to grow and age, the burden of cancer will inevitably increase, even if current incidence rates remain the same. More than half of all cancers worldwide are already diagnosed in the developing countries, and without intervention this proportion is predicted to rise in the coming decades. By 2030, there will be almost 21.4 million new cases diagnosed annually and that there will be over 13.2 million deaths from cancer *NCI, (2013)*.

Leukemia is a group of disorders characterized by the accumulation of malignant white cells in the bone marrow

and blood, these abnormal cells cause symptoms due to bone marrow failure and infiltration of organs ***Grigoropoulos, et al. (2013)***

Chemotherapy is systemic cancer treatment using cytotoxic drugs to destroy malignant cells. It is used for widespread disease or when there is a high risk of recurrence. Chemotherapy may be used alone as a curative measure or can be used as adjuvant chemotherapy or radiation therapy. Chemotherapy has a major effect on the bone marrow cause develop infection, sore mouth, fever, anemia, fatigue, weakness, bleeding, nosebleeds, and blood in urine or stool. Chemotherapy has a major effect on the gastrointestinal tract by cause vomiting, nausea, constipation and loss of weight ***Yarbo et al., (2011)***.

A Patient with leukemia suffer from many health problems and complications as a result of the disease process or the course of treatment. ***Gyasi et al., (2013)***.

Family caregiver is a challenge. The responsibility of caring for dependent people at home involves the adoption of behaviors and actions that may be indicative of proficiency, particularly when the dependency is the result of an acute event or sudden illness. The preparation of family caregivers must begin in the hospital and should only be concluded

when the family caregiver demonstrates cognitive and instrumental skills to provide care *Oliveira et al., (2011)*.

Caregivers need to perform complex medical tasks, supervise patients, make decisions, solve problems, provide emotional support and comfort, and coordinate care. Using these skills, caregivers administer medications, plan and provide meals, handle medical equipment, and provide direct care such as wound care and lifting and turning. Caregivers also provide custodial care, transportation and advocacy *Levine, et al., (2013)*.

The ability of the family caregiver to provide quality care and contribute to the management of chronic disease is a vital health care resource, Health care providers should be supportive of family caregivers and help them acquire knowledge and skills in order to maximize quality care. Caregivers for leukemia patient require knowledge, skills, and judgment carry out the tasks of care patients, and research has shown that caregivers who feel prepared to deliver care have less burden *Stewart et al., (2012)*.

Coping is expending conscious effort to solve personal and interpersonal problems, and seeking to master, minimize or tolerate stress or conflict. Effectiveness of the coping efforts depends on the type of stress and/or conflict

Weiten et al., (2011). Coping responses are partly controlled by personality (habitual traits), but also partly by the social environment, particularly the nature of the stressful environment (*Charles et al., 2011*).

Significance of the study:

A proper patient-caregiver relationship will contribute to a positive caregiver' experience and may decrease rates of patient hospitalization and institutions. More than 65 million family caregivers play a major role in the health and quality of life of individuals with acute and chronic illnesses *National Alliance for Caregiving, (2012).*

Caregiver practice has a significant impact on the condition of leukemic patients, whether they are at home or hospitalized. Promoting opportunities to take care of leukemia patients, participate in caregiver support groups, as well as discussion between nurses and caregivers can empower caregivers by enhancing their competence in caring, these activities at the same time also create opportunities for caregivers to share their feelings and decision making when selecting strategies *Turner & Macdonald, (2011)and Renshaw, (2013).*

AIM OF THE STUDY

The aim of this study was to implement follow up care for family caregiver and patients with Leukemia undergoing chemotherapy.

This aim was achieved through:

- 1- Determining the leukemic patients' needs and Problems related to their daily living activities.
- 2- Assessing the patients' and family caregiver level of knowledge about side effects of chemotherapy.
- 3- Assessing the patient's and family caregiver level of practice about the care of side effect of chemotherapy.
- 4- Detecting the family caregivers' coping pattern related to patient Care.
- 5- Developing and implementing the follow up care for family Caregiver and patients at home.
- 6- Evaluating the effect of the follow up care on the level of Knowledge, practice and daily living activities Modifications.

Research Hypothesis:

Follow up care at home will improve the patients' and the family's level of knowledge and practices related to control the side effect of chemotherapy, daily living activities and modified positive coping pattern.

Chapter (1)

Overview about Leukemia

Concept of leukemia:

The term of leukemia refers to a neoplasm of hematopoietic tissue. In contrast to solid tumor, which forms nodular deposits, leukemia cells diffusely infiltrate the bone marrow and lymphoid tissues, spill over into the bloodstream, and infiltrate throughout the various organs of the body (*Bratt-Wyton, 2013*).

Leukemia is cancer of the blood and develops in the bone marrow, the soft inner part of bones where new blood cells are made. When a patient has leukemia, the bone marrow produces white blood cells that do not mature correctly. Normal, healthy cells only reproduce when there is enough space for them. The body will regulate the production of cell by sending signals of when to stop producing *Leukemia & Lymphoma Society, (2013)*.

Leukemia is a type of cancer found in blood and bone marrow and is caused by the rapid production of abnormal white blood cells. These abnormal white blood cells are not able to fight infection and impair the ability of the bone marrow to produce red blood cells and platelets. *Leukemia & Lymphoma Society, (2013) and National Cancer Institute, (2013)*.

Epidemiology of Leukemia:

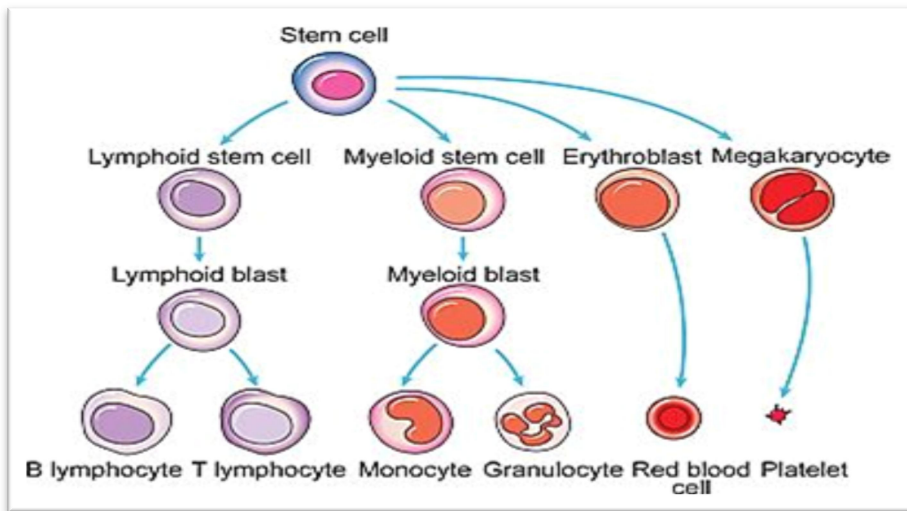
An estimated combined total of 162, 020 people in the US is expected. New cases of leukemia, lymphoma and myeloma are expected to account for 9.8 percent of the estimated 1, 658, 370 new cancer cases diagnosed in the US in 2015. The incidence is higher in male than females. Approximately every 3 minutes one person in the United States (US) are diagnosed with a blood cancer *American Cancer Society, (2013)*. In Egypt, 64 leukemia cases were registered 2013. These cases were 36 males and 28 females. They represented. 6% of all incident cancers, accounting for 6.9% and 4.5% of male and female cancers respectively. Leukemia ranked fourth in males and females. Mean age at diagnosis in males was 24.8 years with a median of 20 years. Mean age at diagnosis in females was 32.6 with a median of 36 years . Approximately every 5 minutes one person in the Egypt is diagnosed with a cancer. Approximately every 5 minutes three persons in 2050 *Amal, (2015)*.

Pathophysiology of leukemia:

Leukemia is a type of cancer with the uncontrolled production of immature white blood cells (usually blast cells) in the bone marrow. As a result, the bone marrow becomes overcrowded with immature, nonfunctional calls and production of normal blood cell is greatly decreased. In a

healthy person, the bone marrow makes blood stem cells (immature cells) that become mature blood cells over time. A blood stem cell may become a myeloid stem cell or a lymphoid stem cell *Sharma, (2013)*.

Figure (1): Production of normal blood cell.



American Cancer Society, (2012). Cancer Facts & Figures, (2012). Atlanta: American Cancer Society. Available online:

National Cancer Institute, (2012) illustrated that A myeloid stem cell becomes one of three types of mature blood cells:

- * Red blood cells that carry oxygen and other substances to all tissues of the body.
- * Platelets that form blood clots to stop bleeding.
- * White blood cells that fight infection and disease.

A lymphoid stem cell becomes a lymphoblast cell and then one of three types of lymphocytes (white blood cells).

- * B lymphocytes that make antibodies to help fight infection.
- * T lymphocytes that help B lymphocytes make antibodies that help fight infection.
- * Natural killer cells that attack cancer cells and viruses.

With leukemia, cancer occurs in the stem cells or early precursor leukocyte cell, causing excessive growth of a specific type of leukocyte. These cells are abnormal and their excessive production in the bone marrow stops normal bone marrow production of red blood cells, platelets and mature leukocytes. The number of immature, abnormal white blood cells in the blood is greatly elevated. Leukemia cells can also be found in the spleen, liver nodes and central nervous system.

Etiology of Leukemia:

Experts say that leukemia has different causes. The following are either known causes, or strongly suspected causes. The exact cause of leukemia is unknown, but several etiological factors have been identified *Williams et al. (2013)*.

1. **Genetic factors:** The relationship of genetic factors to the incidence of leukemia has been suggested in certain high-risk families and specific hereditary syndromes. There is some evidence of familial clustering, with a fourfold to sevenfold increase risk in individuals with a family member diagnosed with leukemia. Acquired clonally chromosomal abnormalities are found in 55%-78% of adult patients with acute leukemia and in 90% of secondary leukemia **Musselman et al., (2013).**
2. **Radiation:** Population exposed to ionizing radiation has an increased incidence of leukemia. In addition, early radiologists exposed to excessive irradiation experienced a higher incidence. So, radiation remains the most conclusively identified leukemogenic factor in human beings. Radiation exposure increased risk seen in patients exposed to atomic bomb explosion in japan; early radiologists (before appropriate shielding) and patients irradiated for ankylosing spondylitis **National Cancer Institute, (2013).**
3. **Chemicals:** Chronic exposure to certain chemicals has been associated with an increased incidence of pancytopenia and subsequent AML. These chemicals are produced by natural processes and by industry such as benzene, and aromatic hydrocarbon **Polychronakis et al., (2013).**

4. Drugs: Drugs that demonstrated a relationship to the etiology of acute leukemia include certain alkylating agents and the antibiotic chloramphenicol. Therapy related leukemia now represents 20 -25% of all cases of AML patients and overall median survival are four to eight months the time of greatest risk appears to be the first ten years after treatment *American Cancer Society, (2013).*

Classification of leukemia:

Leukemia is subdivided into a variety of large groups. The first division is between its acute and chronic form. **Acute leukemia**, characterized by a rapid increase in the numbers of immature blood cells. Crowding due to such cells makes the bone marrow unable to produce healthy blood cells. Immediate treatment is required in acute leukemia due to the rapid progression and accumulation of the malignant cells, which then spill over into the bloodstream and spread to other organs of the body. Acute forms of leukemia are the most common forms of leukemia in children *American Cancer Society, (2012).*

Chronic leukemia characterized by the excessive buildup of relatively mature, but still abnormal, white blood cells. Typically taking months or years to progress, the cells

are produced at a much higher rate than normal cells, resulting in many abnormal white blood cells in the blood. Whereas acute leukemia must be treated immediately, chronic form are sometimes monitored for some time before treatment to ensure maximum effectiveness of therapy. Chronic leukemia mostly occurs in older people, but can theoretically occur in any age group *Leukemia& Lymphoma Society, (2013)*.

The second division, the diseases are subdivided according to which kind of blood cell is affected. This split divides leukemia into lymphoblastic or lymphocytic leukemias and myeloid or myelogenous leukemias. In lymphoblastic or lymphocytic leukemias the cancerous change takes place in a type of marrow cell that normally goes on to form lymphocytes, which are infected-fighting immune system cells. Most lymphocytic leukemia involve a specific subtype of lymphocyte, the B cell. In myeloid or myelogenous leukemias, the cancerous change takes place in a type of marrow cell that normally goes on to form red blood cells, some other types of white cells, and platelets *National Cancer Institute, (2013)*.

Acute lymphoblastic leukemia (ALL), is the most common type of leukemia in young children, Standard treatment involve chemotherapy and radiotherapy. The survival rates vary by age: 85% in children and 50% in adult. Sub-types include precursor B acute lymphoblastic leukemia, precursor T acute lymphoblastic leukemia, Burkitt's leukemia, and acute biphenotypic leukemia *Bindler et al., (2012)*.

Chronic lymphocytic leukemia (CLL), most often affects adults over the age of 55. It sometimes occurs in younger adults, but it almost never affects children. Two-thirds of affected people are men. The five-year survival rate is 75% it is incurable, but there are many effective treatments. One subtype is B -cell prolymphocytic leukemia, a more aggressive disease (*National Cancer Institute, 2012*).

Acute myelogenous leukemia (AML), occurs more commonly in adults than in children, and more commonly in men than women. AML is treated with chemotherapy. The five-year survival rate is 40%. Subtypes of AML include acute promyelocytic leukemia, acute myeloblastic leukemia, and acute megakaryoblastic leukemia *Sharma, (2013)*.

Chronic myelogenous leukemia (CML), occurs mainly in adults. A very small number of children also develop this disease. Treatment is with imatinib (Gleevec in US, Glivec in Europe) or other drugs. The five-year survival rate is 90%. One subtype is chronic monocytic leukemia *Leukemia & Lymphoma Society, (2013)*.

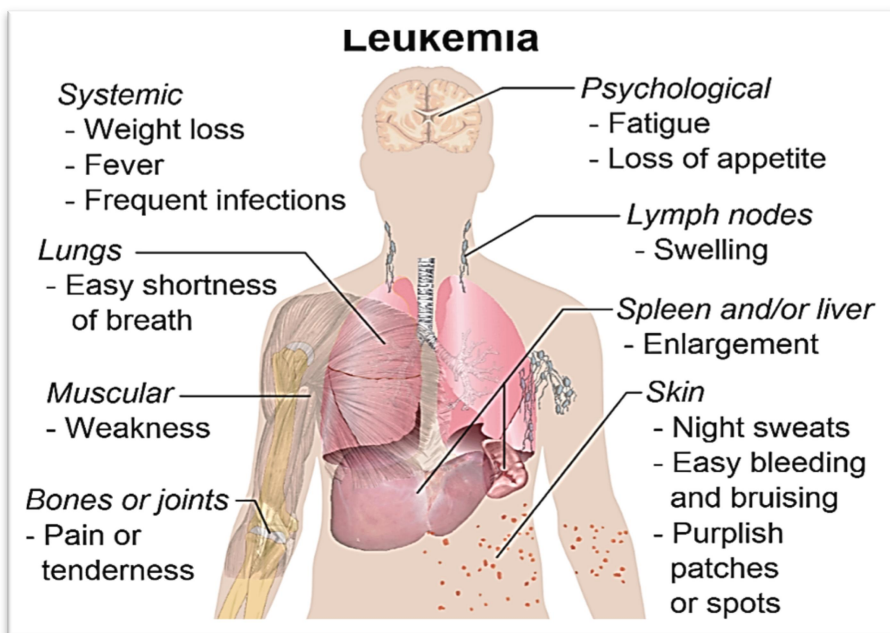
T-cell prolymphocytic leukemia (T-PLL), is a very rare and aggressive leukemia affecting adults; somewhat more men than women are diagnosed with this disease. Despite its overall rarity, it is also the most common type of mature T cell leukemia; nearly all other leukemias involve B cells. It is difficult to treat, and the median survival is measured in a month *Health Communities Staff, (2013)*.

Clinical manifestations of leukemia:

Clarified that clinical manifestations of leukemia include, damage to the bone marrow, by way of displacing the normal bone marrow cells with higher numbers of immature white blood cells, results in a lack of blood platelets, which are important in the blood clotting process. This means people with leukemia may easily become bruised, bleed excessively, or develop pinprick bleeds (petechial). Clinical manifestations of leukemia also include,

frequent infection, ranging from infected tonsils, sores in the mouth, or diarrhea to life- threatening pneumonia or opportunistic infections. Red blood cell deficiency leads to anemia, which may cause dyspnea and pallor *Rowen et al., (2013)*.

Figure (2): Common symptoms of leukemia.



American Cancer Society (2012). Cancer Facts and Figures 2012. Atlanta: American Cancer Society

In acute leukemia, the abnormal cells may collect in the brain or spinal cord (also called the central nervous system or CNS). The result may be headaches, vomiting, confusion, loss of muscle control, and seizures. Leukemia